Genetic Lingua: Speaking Genetics

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• Working Group Members
  – Suzanne Belinson (BCBSA) - Co-Chair
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SPEAKING GENETICS

• Formed last year

• Meet twice a month

• Finalizing 2015 scope

• Addition of an analytical linguist and associated data science team & technology

• In the data collection phase
SPEAKING GENETICS GOALS

- Vision - Uniformly accessible language of genetics
  - Build a meta-language that takes complex concepts in genetic medicine and distills them into a fluid, accessible and comprehensible vocabulary and system of expression that will work across the communication landscape of genetic medicine.

- 2015 Goals
  - Identify communication buckets
  - English only focus
  - Data analysis
    - Identify common language elements in use
    - Prioritization
  - Propose recommendations for prioritized language elements
SPEAKING GENETICS    COMMUNICATION

- Consumer space
- Provider :: Patient communication
- Payer :: Patient communication
- Provider :: Lab communication
- Advocacy Groups:: (Patients, Providers, Government, Funders, Patrons, etc.)
- Research
SPEAKING GENETICS  NEXT STEPS

- Gather and Analyze Data

- Prioritize communication items for language construction

- Develop initial meta-language constructions for evaluation

- Evaluate through testing, including diverse audiences
INVOLVEMENT

FUNDING
Thank You

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